

10 August 2016

HCBS Waiver Unit
Executive Office of Health & Human Services
1 Ashburton Place, 11th Floor
Boston, Massachusetts 02108

Submitted electronically via HCBSWaivers@state.ma.us

Re: Revised Statewide Transition Plan for Compliance with the Home and Community-Based Services (HCBS) Community Rule

TASH New England is the regional affiliate of TASH International, an international leader in disability advocacy committed to achieving equity, inclusion, and opportunity for people with the most significant disabilities and support needs. Our membership includes people with intellectual and developmental disabilities (I/DD), family members, researchers, direct service workers, and other professionals in the I/DD field. We welcome the opportunity to submit the following comments regarding Massachusetts' revised state transition plan for compliance with the CMS Home and Community Based Services Community Rule.

Overall, we are pleased to see that EOHHS and its component agencies have taken the previous round of public comments into consideration in revising the state transition plan submission to CMS. TASH New England has concerns about five major deficiencies in the current state transition plan, especially as pertains to DDS-administered waiver programs (residential, day, and employment waivers).

(1) Insufficiency of reliance on existing DDS licensure and certification requirements to ensure compliance with the Community Rule.

Page 14 of the revised state transition plans reiterates DDS's original assertion that the state licensure and certification process is sufficient to ensure compliance of all vendors with the Community Rule, since the system measures indicators and outcomes related to "community integration, support for developing and maintaining relationships, exercise of choice and control of daily routines and major life decisions, and support for finding and maintaining employment and/or meaningful day activities." The indicators and outcomes measured are important and necessary for determining whether a particular vendor or setting has the spirit of the Community Rule in its services.

While TASH New England fully supports DDS's ongoing collaboration with a Licensure and Certification Workgroup to revise and clarify the standards by including language from the CMS Community Rule, we remain concerned about DDS's confidence in its current policies with use of these procedures. Currently, DDS only mandates assessment of 25% of all settings (randomly sampled) that any individual vendor operates, while also only requiring a minimum of 60% overall compliance with the licensure and certification standards in order to be approved for HCBS waiver funding.¹

¹ Dept. of Developmental Services, Licensure and Certification Manual (July 2010), at 2, 21, *available at* <http://www.mass.gov/eohhs/docs/dmr/manuals/qm-manual-5ed.pdf>.

Even if the indicators and measures used to conduct assessments are in alignment with purpose of the Community Rule (for example, through use of the National Core Indicators), licensing and certifying vendors at only 60% compliance allows vendors to fall far short of the expectations in the Community Rule. Additionally, requiring assessment of only 25% of all settings operated by a single vendor is woefully inadequate to ensure that every setting where people receive services is in compliance. A vendor may operate several settings that go above and beyond the floor established in the Community Rule, while simultaneously operating other settings where service recipients are isolated, denied individualized activities, and unable to exercise choice. DDS's current assessment procedures would fail to identify those settings by licensing and certifying the vendor as a whole without requiring remediation.

(2) Confidence in ability to ensure compliance in all existing residential settings and agency determination that no settings require heightened scrutiny.

Pages 29-30 of the revised plan reiterate the agency's earlier determination that all residential settings either currently comply (1,091) or will comply with some level of changes (2,240 combined), but that no residential settings are unable to meet the requirements. Similarly, page 47 also reiterates the agency's earlier determination that no waiver service delivery settings require heightened scrutiny.

We are highly concerned that this determination is not only inaccurate, but risks continued service provision to vulnerable individuals in settings that have the characteristics of an institution. TASH New England is aware of people with significant disabilities and complex health needs who are living in congregate housing at sites adjacent to or even co-located with the grounds of current and former institutions, which are largely in remote, industrial or business districts, and not meaningfully integrated into the surrounding communities. To best protect the interests of both the state and of service recipients in maximizing community integration, we recommend re-evaluation of this determination. That may start with the 57 settings (served by 14 providers combined) identified as requiring substantial changes to come into compliance, since those settings may be the most likely candidates for heightened scrutiny as institutional-like. We are not confident that all settings in Massachusetts are capable of coming into compliance with the Community Rule.

Additionally, while the revised plan does acknowledge on page 32 the possibility of a determination that a residential setting is not and cannot become compliant, it still provides no timeframe requirements for notification to the service recipient or maximum time for continuity of funding if the service recipient chooses to move to a compliant setting. Lack of specificity as to timeframe could leave vulnerable people without access to financial support for their housing and continuity care while transitioning from receiving services in one setting to another.

(3) Lack of commitment to apply Community Rule requirements to settings providing Day Habilitation services where at least one person is receiving Day Habilitation Supplemental Waiver funding.

The revised state plan provides substantial information on HCBS-funded Community-Based Day Services (CBDS) but only mentions Day Habilitation in passing. In the responses to comments received from the original non-residential and employment addendum, DDS notes on page 5 that day habilitation services “are highly clinical in nature.” While DDS issued a policy statement in September 2014 committing to applying the HCBS Community Rule requirements to all DDS-funded programs and services, we would like to see stronger commitment to ensuring that all people receiving either CBDS or Day Habilitation services, or both, will be afforded meaningful and individualized opportunities for community integration regardless of level of support needs or medical complexity.

People with significant disabilities, high support needs, and complex medical profiles should not be relegated to living in group homes and only experiencing “community” in outings (often not determined by individual interests) with other group home residents and vendor staff, dependent entirely on availability and willingness of vendor staff to provide transportation. That is not integration; it is a farcical interpretation of “being in the community” that superficially meets requirements of community outings around people without disabilities but without meaningfully altering a person’s ability to exercise choice and participate on their own terms. In accordance with the Community Rule requirements, people with disabilities receiving Day Habilitation services for whom work is not currently a goal have the right to activities, programs, and services based on individual desires, needs, and interest, rather than on staff convenience or assumptions about a person’s interests or ability to participate. Further issuance of standards and development of required training should address strategies for implementing individualized day services that presume competence and foster meaningful engagement with the community at large.

(4) Acknowledgement of systemic barriers to more individualized programming and support without creating any benchmarks for progress or improvement to deficient infrastructure.

Page 31 of the revised state plan notes that community-based day services sites currently face challenges to meet the Community Rule requirements including “insufficient funding to enable consistent individualization, access and integration; staff ratios that are not sufficient to facilitate individualized activities; individuals from different populations with varying needs; lack of access to public transportation and unclear standards/definitions/criteria.”

As many of us have disabilities, support family members with significant disabilities, or have worked in service provision, we can appreciate and understand such systemic challenges; however, we also expect that it is the state’s responsibility to develop the infrastructure – and all necessary benchmarks and goals for meeting them – to begin addressing those challenges. Nevertheless, as written, the revised state plan acknowledges systemic barriers, but essentially resigns itself to their perpetual, unchanged existence. We encourage final revisions to incorporate measurable benchmarks and goals for progress or improvement.

(5) Continued use of group supported employment settings that are inconsistent with the spirit of the Community Rule.

The revised transition plan does note that group supported employment that pays less than minimum wage is scheduled to be phased out by the end of June 2018. However, page 34 describes DDS's intent to initiate remedial action designed to bring group supported employment settings into compliance with the Community Rule. We are concerned that group supported employment is itself fundamentally inconsistent with the spirit of the Community Rule. Group supported employment is a category sufficiently broad to allow work settings substantially similar to congregate work or shelter-like arrangements.

In such settings, service recipients with disabilities may be theoretically integrated into a larger workplace alongside colleagues with and without disabilities, but in reality are isolated and stigmatized due to group placement. Consistent with DDS regulatory requirements (in conjunction with the HCBS Community Rule), such workers may receive minimum wage and be afforded access to the same workplace amenities as workers without disabilities, but co-location with workers without disabilities is no guarantee of meaningful community integration if, for instance, the workers with disabilities have little opportunities to socialize outside their own cluster. Additionally, group supported employment may lack capacity to implement more individualized approaches to employment by permitting clustering of workers with significant disabilities in the same workplace.

Finally, we encourage DDS to update the state transition plan to address the problems posed by educational collaboratives or school districts that currently engage in the practice of placing students with disabilities in sheltered workshops or segregated group supported employment programs, ostensibly for education and development of prevocational skills. Even if these types of programs are primarily funded through school districts and not considered vocational in nature, thus existing outside the scope of regulations applicable to waiver-funded programs, students with significant disabilities who are currently in these placements are at highest risk for referral as adults to less individualized, potentially segregated or isolating group supported employment programs, which do fall under the scope of DDS regulatory authority.

We are happy address any questions or requests for clarification about our comments, and look forward to engaging with the state further as it moves forward in the transition process. Please direct any questions to Lydia X. Z. Brown at lydia@autistichoya.com or (202) 618-0187. Thank you again for your time and attention, as well as your ongoing work to update the Massachusetts services system for people with disabilities.

Sincerely,

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